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ABSTRACT

The paper describes a state survey to identify mentally retarded adults most in need of services to diminish the risk of institutionalization. The surveys examined nine areas, including medical condition and needs, self-care skills, adaptive and independence skills, maladaptive behaviors, and stresses and demands on the caregiver. Among results were that 70% of the adults were under age 30, more than 75% were women, 33% of all caregivers were over the age of 60 with almost half the families reporting a variety of problematic situations. Additional findings revealed that almost 30% of the adults were in the severe or profound range of mental retardation; that the adults varied from extreme dependence in self-care to high levels of competence; and that maladaptive behavior was not an overwhelming problem. Demographic varibles associated with families expressing urgency for residential placement included reports of more stressful personal situations including financial problems, responsibilities for child care or care of an elderly family member, serious health problems, and personal problems. (CL)

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THE COMING OF AGE OF MENTALLY RETARDED ADULTS: AN EMERGING CRISIS

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The Coming of Age of Mentally Retarded Adults: An Emerging Crisis

The acceptance of the philosophy of normalization over the past two decades has made community based programming the preferred method of offering services to mentally retarded adults. Institutionalization is no longer the alternative of choice, and for all but the most severely disabled, families have assumed primary responsibility for raising their mentally retarded children and coordinating available services. While caring for a mentally retarded child is not without stress; education, training, and supportive services are available, as mandated by Public Law 94-142, the Education of all Handicapped Children Act. Unfortunately, the specialized programs available to mentally retarded children are much less available for mentally retarded adults. The educational system is not required to provide services for persons beyond the age of 21 and resources for adults, such as vocational training workshops, activity centers, and supportive services are drastically limited. Further, there is a critical shortage of community based residential alternatives for mentally retarded adults. The vast majority of the community residential placements created have been done so as a part of the massive transfer of individuals from institutions to the community. Thus, too often graduation from school for the community based mentally retarded adult is followed by a programming void in which developmental gains may be lost.

Without adequate programs, the normal family pattern of children requiring less care and then leaving home as relatively

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INDEPENDENT ADULTS IS REVERSED. AS PARENTS PASS THE USUAL CARE-GIVING STAGE OF THEIR LIVES- COPING WITH A RETARDED ADULT MAY BECOME DIFFICULT, PARTICULARLY WHEN SERVICES ARE LIMITED. FOR FAMILIES WHO ARE NO LONGER ABLE TO PROVIDE ADEQUATE CARE AND SUPERVISION FOR THEIR MENTALLY RETARDED DEPENDENTS, INSTITUTIONAL-IZATION LOOMS AS A REGRETABLE, ALBEIT NECESSARY OPTION.

THIS DEVELOPMENTAL CRISIS AMONG MENTALLY RETARDED ADULTS IS EMERGING NOW. THE FIRST GENERATION OF MENTALLY RETARDED INDIVIDUALS TO BE RAISED AT HOME AND RECEIVE SERVICES UNDER THE AUSPICES OF PUBLIC LAW 94-142 ARE REACHING ADULTHOOD. THOSE MENTALLY RETARDED PERSONS WHO WOULD HAVE BEEN INSTITUTIONALIZED IN THE 60'S OR EARLY 70'S ARE CONTINUING TO LIVE WITH PARENTS WHO ARE AGING. IN ORDER TO DETERMINE THE EXTENT OF THE CRISIS, WE HAVE INITIATED AN INTENSIVE STATEWIDE SYSTEM TO LOCATE FAMILIES CARING FOR MENTALLY RETARDED ADULTS. USING THE SURVEY DATA, OUR GOAL HAS BEEN TO DEVELOP A PROCEDURE TO IDENTIFY INDIVIDUALS MOST IN NEED OF SERVICES TO DIMINISH THE RISK OF INSTITUTIONALIZATION.

METHODS

IN COLLABORATION WITH THE MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES ADMINISTRATION, ALL ADVOCACY AND SERVICE AGENCIES IN THE STATE OF MARYLAND WERE ASKED TO DISTRIBUTE SURVEY FORMS TO ALL KNOWN MENTALLY RETARDED ADULTS LIVING WITH THEIR FAMILIES (AND WERE THEREFORE NOT RECEIVING RESIDENTIAL SERVICES). FROM THE INITIAL CASE-FINDING EFFORT 2,338 FAMILIES WERE IDENTIFIED. SINCE SERVICE AGENCIES PROVIDED THE PRIMARY SOURCE OF REFERRAL, PERSONS WHO WERE NOT ON WAITING LISTS FOR RESIDENTIAL SERVICES OR DAY PROGRAMS MAY NOT HAVE BEEN CONTACTED.

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THE CAREGIVER FORM OF THE COMMUNITY NEEDS SURVEY WAS SENT TO ALL IDENTIFIED FAMILIES. THIS QUESTIONNAIRE INCLUDES DEMOGRAPHIC INFORMATION ABOUT THE ADULT AND FAMILY, AS WELL AS ITEMS FROM NINE AREAS:

1. MEDICAL CONDITION AND NEEDS
2. SPECIAL PHYSICAL AND ENVIRONMENTAL NEEDS
3. SELF-CARE SKILLS
4. ADAPTIVE AND INDEPENDENCE SKILLS
5. MALADAPTIVE BEHAVIORS
6. SERVICE UTILIZATION
7. SERVICE RECOMMENDATIONS
8. CAREGIVER'S ESTIMATION OF URGENCY FOR RESIDENTIAL PLACEMENT
9. STRESSES AND DEMANDS ON THE CAREGIVER

RESULTS

AS ANTICIPATED, INITIAL DEMOGRAPHIC STATISTICS REVEAL THE PREPONDERANCE OF YOUNG MENTALLY RETARDED ADULTS, 70% UNDER AGE 30. 41% WERE BETWEEN THE AGES OF 21 AND 25. IT WOULD APPEAR THAT THIS AGE DISTRIBUTION REFLECTS THE MORE ACTIVE ATTEMPTS OF PARENTS OF PERSONS WHO HAVE RECENTLY LEFT THE SCHOOL SYSTEM TO OBTAIN SERVICES.

DISPLAY SLIDE #2

MORE THAN THREE-FOURTHS OF THE PRIMARY CAREGIVERS ARE WOMEN, AND A THIRD OF ALL CAREGIVERS ARE OVER AGE 60. WITH OVER 15% OF THE CAREGIVERS BEING OVER THE AGE OF 65 THERE IS CLEAR INDICATION OF THE NECESSITY FOR THE STATE TO PLAN FOR SERVICES FOR THESE PERSONS.

DISPLAY SLIDE #3

FORTY-FOUR PERCENT OF THE CAREGIVERS ARE EMPLOYED OUTSIDE THE

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HOME; 39% ARE SINGLE, WIDOWED, OR DIVORCED; AND ALMOST HALF THE FAMILIES REPORTED A VARIETY OF PROBLEMATIC SITUATIONS INCLUDING FINANCIAL PROBLEMS, POOR HEALTH, ELDERLY OR ILL FAMILY MEMBERS, AND PERSONAL PROBLEMS OF THE CAREGIVER.

THE MENTALLY RETARDED ADULTS SAMPLED REPRESENTED A WIDE RANGE OF FUNCTIONAL LEVELS.

DISPLAY SLIDE #4

ALMOST 30% OF THE ADULTS WERE IN THE PROFOUND OR SEVERE RANGE OF MENTAL RETARDATION, 37% WERE IN THE MODERATE RANGE, AND 33% WERE IN THE MILD OR BORDERLINE RANGE. AS EXPECTED, IQ LEVEL WAS HIGHLY ASSOCIATED WITH BOTH SELF-HELP SKILLS AND ADAPTIVE SKILLS.

DISPLAY SLIDE #5

FROM THIS SLIDE IT IS EVIDENT THAT THE MENTALLY RETARDED ADULTS VARIED FROM EXTREME DEPENDENCE IN SELF-CARE (10% WERE NOT TOILET TRAINED AND ANOTHER 13% REQUIRED ASSISTANCE IN TOILETING) TO HIGH LEVELS OF COMPETENCE (39% WERE INDEPENDENT IN ALL AREAS OF SELF-CARE).

DISPLAY SLIDE #6

AS SHOWN IN THIS SLIDE, ADAPTIVE SKILLS ARE A MEASURE OF THE PERSON'S CAPACITY IN INDEPENDENT LIVING AND ENCOMPASS A RANGE OF FIFTEEN TASKS FROM WALKING AND TALKING TO SHOPPING AND MAKING CHANGE. THE EVERAGE NUMBER OF ADAPTIVE SKILLS COMPLETED WAS 8.45, RANGING FROM 6% OF THE ADULTS COMPLETING ALL TASKS AND 1% UNABLE TO COMPLETE ANY TASKS.

MALADAPTIVE BEHAVIOR WAS NOT AN OVERWHELMING PROBLEM IN THIS SAMPLE. WHILE A MAJORITY HAD NO REPORTED INCIDENTS OF MALADAPTIVE BEHAVIOR, DESTRUCTION OF PROPERTY AND PHYSICAL AGGRESSION WITH FAMILY MEMBERS WERE THE MOST FREQUENTLY REPORTED PROBLEMS.

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SEVERAL QUESTIONS ADDRESSED THE NEED FOR RESIDENTIAL PLACEMENT. FIFTEEN PERCENT OF THE FAMILIES CLAIMED THAT THEIR NEED FOR RESIDENTIAL PLACEMENT WAS SO URGENT THAT THEY COULD NOT MAINTAIN THEIR PRESENT SITUATION. IN ORDER TO BETTER UNDERSTAND THE CONDITIONS THAT LED FAMILIES TO CLASSIFY THEIR SITUATION AS URGENT AND IN CRISIS, WE ANALYZED ALL THE DEMOGRAPHIC VARIABLES BY THE FAMILY'S LEVEL OF URGENCY.

DISPLAY SLIDE #7

ADULTS ASSOCIATED WITH FAMILIES IN CRISIS WERE SLIGHTLY YOUNGER, WERE MORE RETARDED, AND HAD FEWER ADAPTIVE SKILLS THAN ADULTS IN MORE STABLE FAMILIES. HOWEVER, THE TWO GROUPS OF ADULTS DID NOT DIFFER IN DEPENDENCY (SELF-CARE) SKILLS. WHEN MALADAPTIVE BEHAVIORS WERE CONSIDERED FAMILIES REPORTING A CRISIS SITUATION WERE SIGNIFICANTLY MORE LIKELY TO HAVE A MENTALLY RETARDED ADULT WHO WAS DESTRUCTIVE, AGGRESSIVE TO SELF AND OTHERS, DISPLAYED INAPPROPRIATE SEXUAL BEHAVIOR, DISTURBED OTHERS AT NIGHT, AND HAD A HISTORY OF PSYCHIATRIC HOSPITALIZATION.

THE DISTINCTION BETWEEN FAMILIES CLAIMING AN URGENT NEED FOR RESIDENTIAL SERVICES AND MORE STABLE FAMILIES WAS ACCENTUATED IN THE COMPARISON OF CAREGIVER STRESS FACTORS.

DISPLAY SLIDE #8

IN SIX OUT OF SIX CATEGORIES FAMILIES IN CRISIS REPORTED MORE STRESSFUL PERSONAL SITUATIONS, INCLUDING FINANCIAL PROBLEMS, RESPONSIBILITIES FOR CHILD CARE OR CARE OF AN ELDERLY FAMILY MEMBER, SERIOUS HEALTH PROBLEMS, AND PERSONAL PROBLEMS.

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Discussion

These results demonstrate the complex interplay between both individual and family variables in contributing to a caregiving situation that considers itself to be in crisis. While the adults in crisis situations were problemmatic and required close supervision, the families were often elderly with a variety of problems not directly related to the presence of a mentally retarded dependent. In order to determine which individuals are most in need of the limited day programs and residential placements available through the state's resources, we have designed, and are in the process of testing, a prediction profile combining salient individual and family characteristics. As mentally retarded persons continue to live within their natural families, additional research extending beyond individual characteristics will be necessary to identify ways to avoid the emerging developmental crisis of mentally retarded adults residing in declining caregiving environments.

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SLIDE #1

COMMUNITY NEEDS SURVEY

1. MEDICAL CONDITION AND NEEDS
2. SPECIAL PHYSICAL AND ENVIRONMENTAL NEEDS
3. SELF-HELP SKILLS
4. ADAPTIVE AND INDEPENDENCE SKILLS
5. MALADAPTIVE BEHAVIORS
6. SERVICE UTILIZATION
7. SERVICE RECOMMENDATIONS
8. CAREGIVER ESTIMATION OF URGENCY FOR RESIDENTIAL PLACEMENT
9. STRESSES AND DEMANDS ON CAREGIVER

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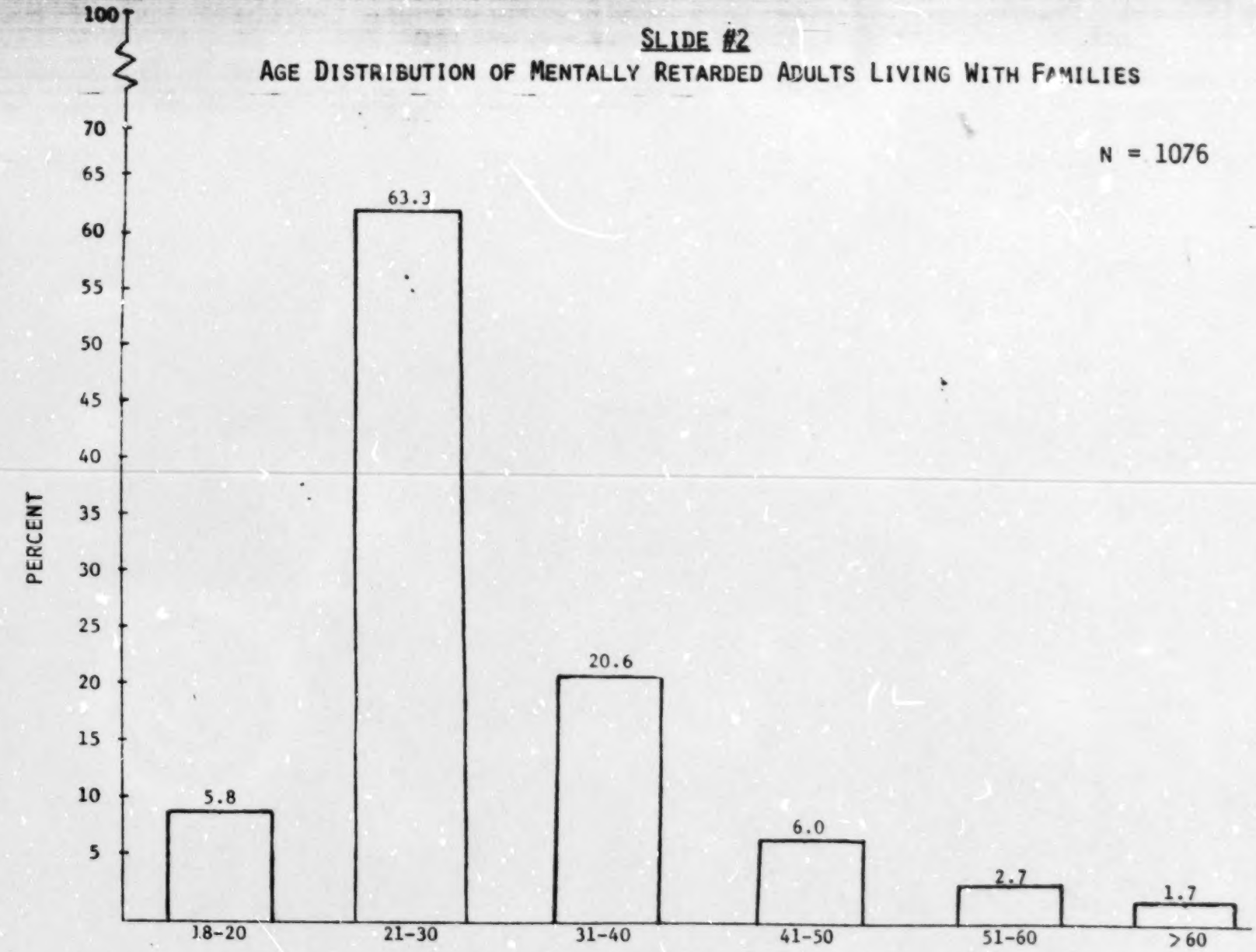
SLIDE #2

AGE DISTRIBUTION OF MENTALLY RETARDED ADULTS LIVING WITH FAMILIES

N = 1076



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SLIDE #3

AGE DISTRIBUTION OF CAREGIVERS OF MENTALLY RETARDED ADULTS

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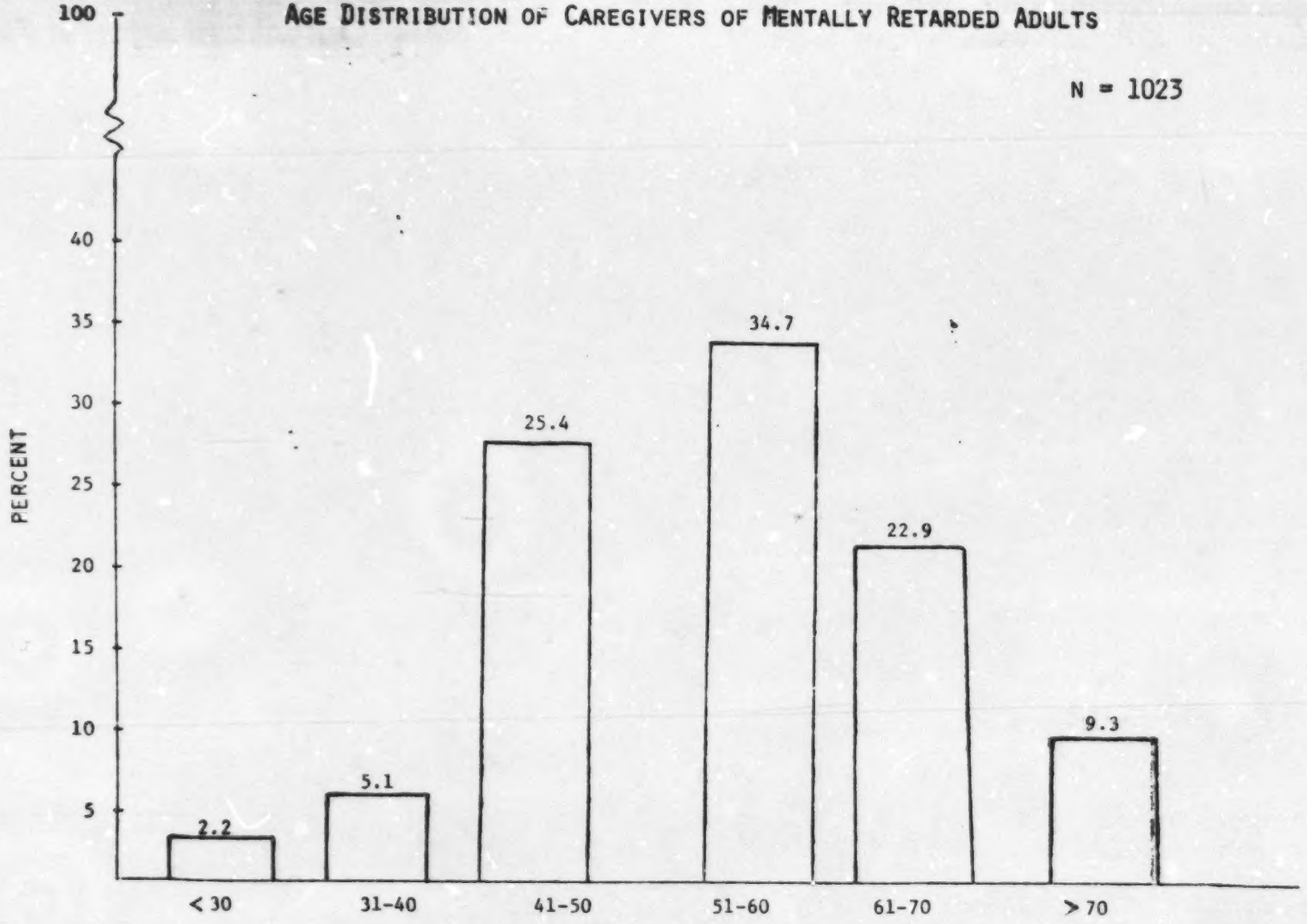

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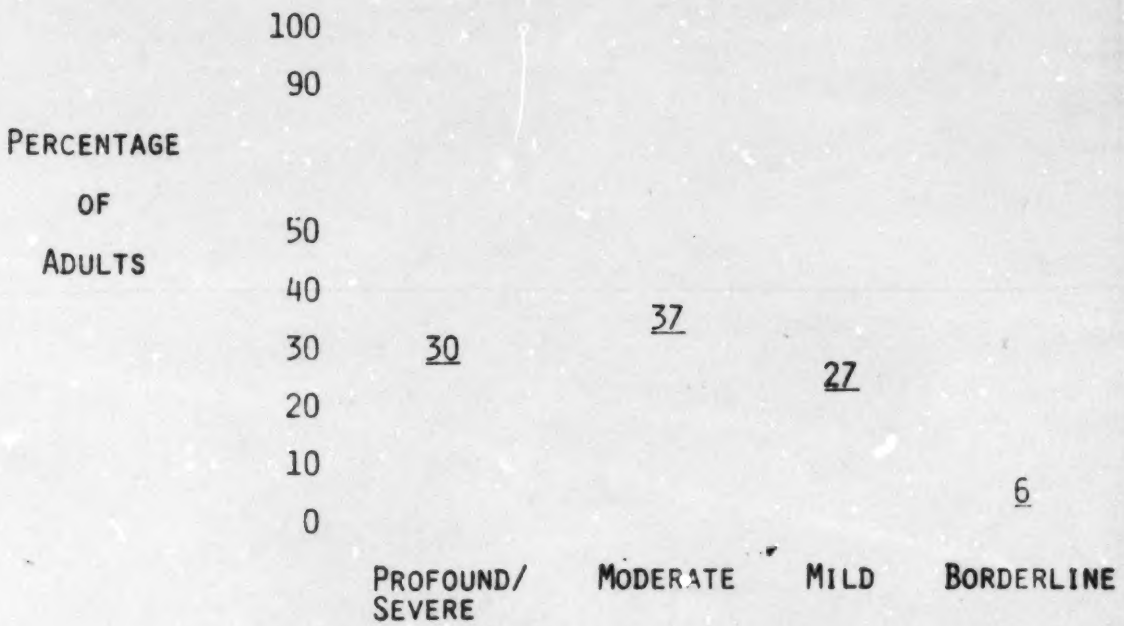
SLIDE #4

LEVEL OF RETARDATION



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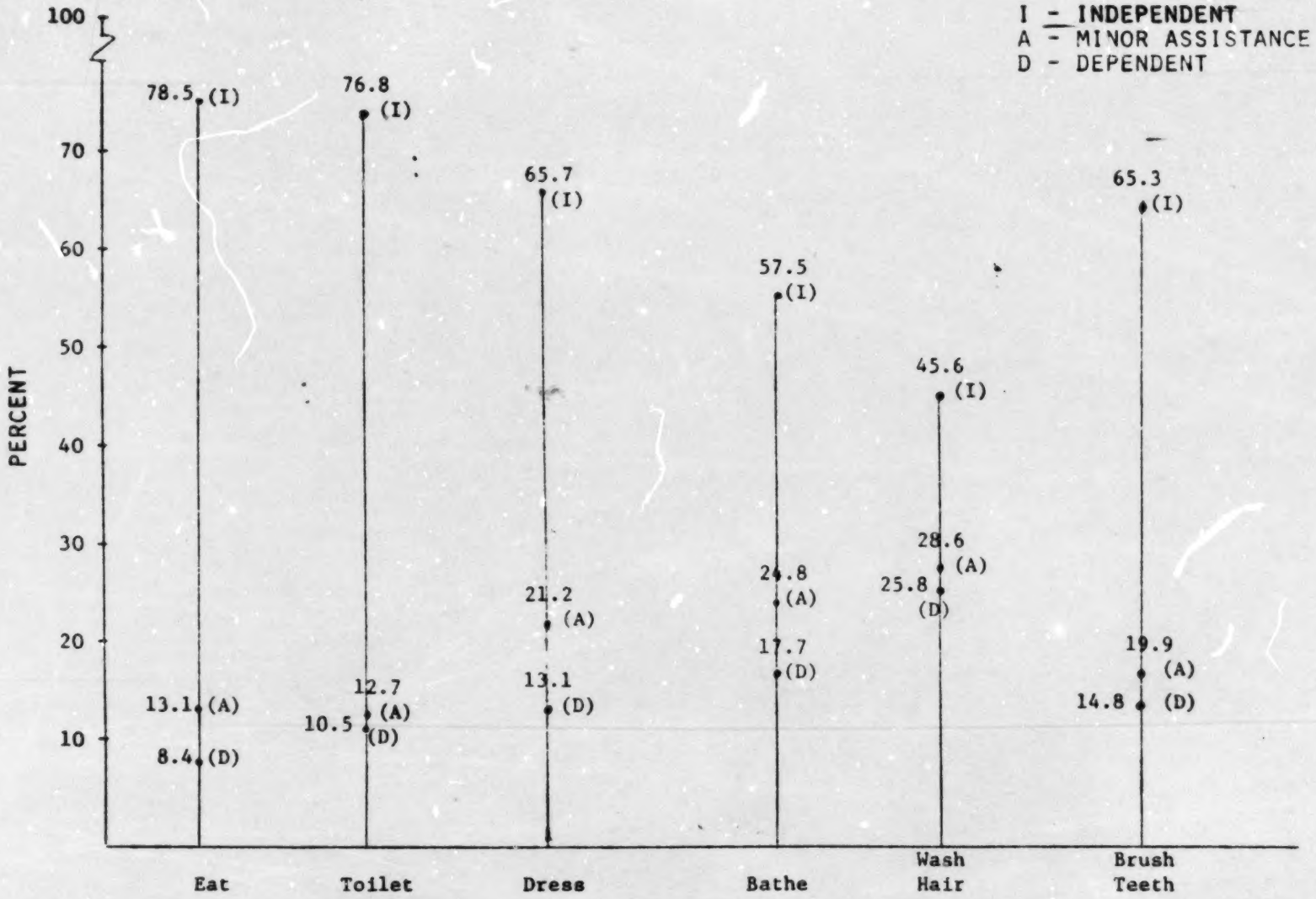
SLIDE #5

SELF CARE SKILLS OF MENTALLY RETARDED ADULTS LIVING WITH FAMILIES



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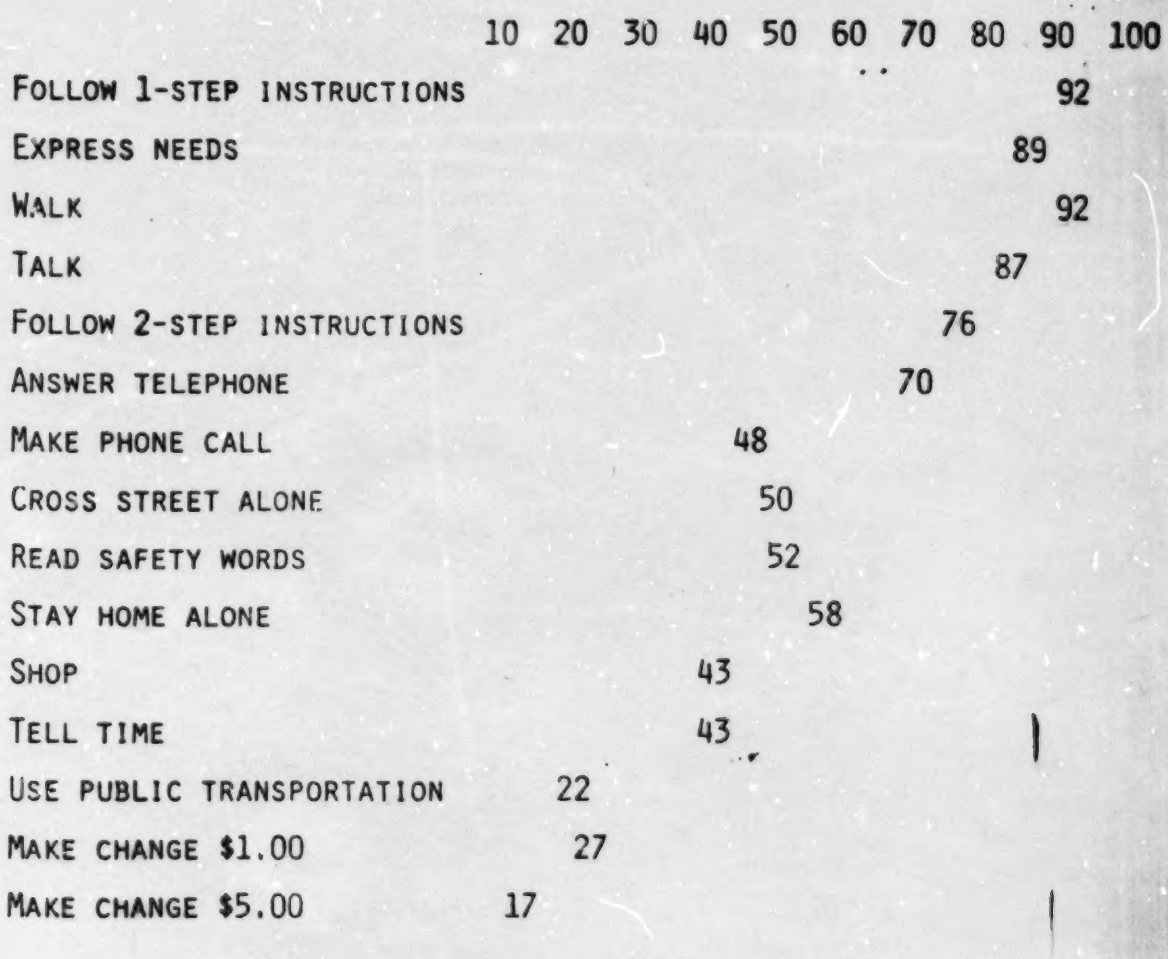
SLIDE #6

ADAPTIVE BEHAVIORS



X = 8.45 ITEMS COMPLETED SUCCESSFULLY

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SLIDE #7

COMPARISON BETWEEN INDIVIDUALS FROM CRISIS FAMILIES AND INDIVIDUALS FROM STABLE FAMILIES

	PERCENT	
	CRISIS FAMILIES	ALL FAMILIES
LESS THAN AGE 31	74	69
RETARDATION PROFOUND/SEVERE	38	30
ADAPTIVE SKILLS		
MALADAPTIVE BEHAVIORS		
DESTROYS PROPERTY	34	18
DISTURBS OTHERS AT NIGHT	36	18
HARMS SELF	27	14
HARMS OTHERS	22	12
INAPPROPRIATE SEXUAL BEHAVIOR	15	9

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SLIDE #8

FAMILY STRESS FACTORS

	PERCENT	
	CRISIS FAMILIES	STABLE FAMILIES
FINANCIAL PROBLEMS	29	13
CAREGIVER - ILL HEALTH	33	15
FAMILY - ILL HEALTH	19	9
PERSONAL PROBLEMS	33	13
FAMILY PROBLEMS	33	15
CHILD CARE RESPONSIBILITIES	16	4

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